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TRANSFORMING LIVES IN ETHIOPIA

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SNAPSHOTS FROM THE FIELD



Family Health  
International



**Impact** Implementing  
AIDS Prevention  
and Care Project



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Cover photo: Andarge Zemene is better able to manage his illness with help from FHI's home- and community-based care program. Photos by Steve Taravella/FHI.

**A** Andarge Zemene has a strong voice and bright eyes, but his body is failing him. He coughs violently from tuberculosis, remains prostrate because he is too weak to stand, and has lost so much weight from HIV that his skeletal frame feels to him “like a dead body.”

For the past nine months, Andarge, 35, has lived in a one-room shack in an Addis Ababa slum with five strangers, a family that took him in because they believed God would favor them for doing so. He sleeps in a corner of the room—actually, lies here most of the time—grateful for this tiny piece of cold floor covered in dirty plastic. It’s worse at night, when he must compete for floor space with day laborers who pay the shack’s owner 50 cents a night for shelter. During the day, he misses company, so he sometimes asks the little girl who lives there to invite other children to come play beside him.

Andarge likely could benefit from antiretrovirals, but their cost is high in Ethiopia and, since his only family is a father who lives far away, “nobody can support me for the medicine. I have a problem just getting food.”

But for Andarge, a former Ethiopian soldier and beer factory worker, life could be much harder. For one thing, the people he lives with understand his needs: The head of this family is himself HIV-positive. Most importantly, Andarge receives home- and community-based care services developed by Family Health International, a U.S.-based nongovernmental organization, and the local NGO Hiwot HIV/AIDS Prevention, Care and Support Organization (HAPCSO).

During a recent visit, a caregiver from this program brought Andarge flour and sugar. The caregiver washed his body, shaved his head to free him of lice, prepared him a meal, and gave him the blue sheets and heavy green blanket that now keep him warm. Previously, he slept directly on the shack’s cold floor. Without help from the FHI/HAPCSO program, “I would have died immediately,” he said.

The impact of this home-based care program—which is funded by the U.S. Agency for International Development (USAID)—is evident far beyond the shack where Andarge sleeps. The program has reached more than 3,100 people since it began operating in September 2003, including 1,500 orphans and vulnerable children. Within a few minutes’ drive, one can find HAPCSO staff and volunteers helping other HIV-positive Ethiopians, such as:

- **Dejene Mohammed**, who has lost his wife, a son and a daughter to HIV. Not to mention toes and fingers to leprosy. On a recent day, Dejene was visited by Sister Yewagnesh, a HAPCSO nurse who came to change the dressing on his left leg. The dressing is not for HIV-related sores, but for burns he experienced when hot tea fell on him. The wounds are large and raw and must be treated tenderly. Sister Yewagnesh is careful as she removes dead skin and covers the wound with sterile gauze to prevent infection. Dejene lives here with one of his surviving children, and clearly his family has come to depend upon Yewagnesh. While his adult daughter, crouching on the floor, prepares coffee for

Yewagnesh, his adult son tells a visitor that HAPCSO “does a lot. Even if we had a job, we could not do much.”

- **Huluageresh Tadesse**, who lost her nine-year-old daughter to AIDS and tuberculosis six months ago. Huluageresh is 29 but looks much older. On a recent afternoon, she is so weak she remains practically motionless, curled up under a blanket. A HAPCSO volunteer caregiver visits three times a week, bringing medicine to help her cope with TB, pervasive skin rashes, coughs and other maladies. The caregiver also brings some basic necessities, like soap and cooking oil. Huluageresh lives with her five-year-old son, who is as energetic as his mother is fatigued. Sometimes Huluageresh’s caregiver brings him small books.

This home-based care program is a compelling lesson in collaboration among a donor (USAID), a global implementing agency (FHI), a local implementing agency (HAPCSO), the local government (the Addis Ababa Health Bureau and the Addis Ababa HIV/AIDS Prevention and Control Office) and community institutions that at first did not see a clear role for themselves in this kind of service (*idirs*, traditional Ethiopian burial societies). In a city with an HIV prevalence rate of about 15 percent, their challenge was great. But with careful planning and a spirit of cooperation among partners, more than 900 people have so far been trained to help meet critical health needs for residents who otherwise might suffer alone. This network can serve as a useful model for agencies elsewhere.

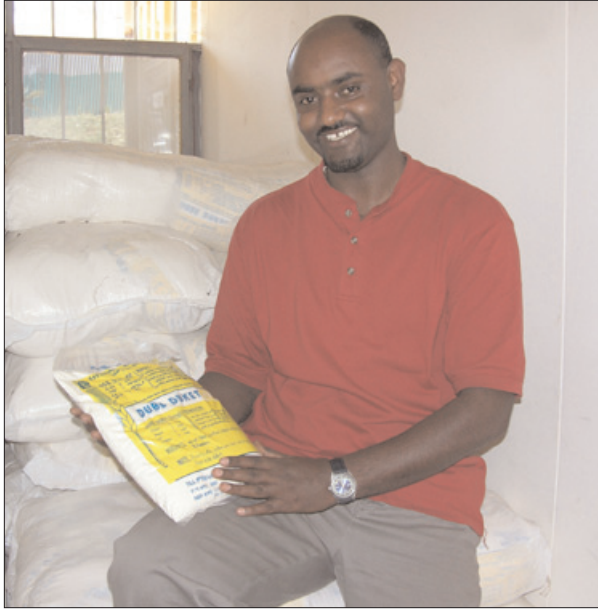
Encountering an increasing need among people who had little access to health care—and no means to reach it if they did—FHI began designing a home-and community-based care project in March 2003 with USAID support.

“Working together, we have created something meaningful. The network is building the community’s capacity to help individuals and families affected by AIDS and poverty. It’s improving quality of life, and helping transform the health system itself,” says Francesca Stuer, FHI’s country director for Ethiopia.

## FINDING THE CAREGIVERS

For the volunteer caregivers who are central to this effort, the project turned to *idirs*, the traditional burial societies that help families when a death occurs and during the mourning period that follows.

Funeral services are an important part of Ethiopian culture, so *idirs* are a valued part of society here. Most Ethiopians pay a monthly membership fee to belong to an *idir*, and some might belong to several. They are formed around common characteristics, such as neighborhood, ethnic identity, workplace or religious affiliation. Each one typically represents several hundred households, and payments (typically 5-10 birr/month) are collected at a fixed date and place. With swelling numbers of HIV deaths threatening to bankrupt some *idirs* and cause others to increase



*Program Coordinator Ephrem Fikre with some of the wheat flour that is provided twice monthly to poor, HIV-positive clients struggling to meet basic nutritional needs.*

Photo: Francesca Stuer

their fees, FHI contacted idir leadership committees to assess their interest in care and support activities for people with HIV.

Engaging idirs did not take much persuasion, explains Worknesh Kereta, FHI's team leader for home- and community-based care. Idir leaders have long operated with a strong sense of community service and leaders hold their positions at no pay. In June 2003, FHI drew 1,500 idir representatives to a one-day HIV sensitization workshop, where the importance of caring for the chronically ill, not just those with HIV, was stressed. The presence of local elected government officials (the meeting was opened by the city's mayor) increased the idirs' comfort level.

After hearing presentations on the nature of home-based care, the prevalence of HIV in Addis Ababa, and the need for care and support

services, participants were divided into small groups by geographic district to discuss particular issues. The idirs showed great interest in supporting people with HIV—but FHI knew the project should begin with only a few of the most engaged before scaling up to idir institutions as a whole. From each of 10 *Kifle Ketemas* (sub-cities), two idirs were selected, based on specific criteria:

- They had to represent more than 350 people.
- They had to serve a densely-populated area with high HIV prevalence.
- They had to already be active, such as by having begun support services on their own.
- They had to serve people who don't already receive HBC services from other agencies.

The 20 idirs that stepped forward received a second, more intense, day-long training. Here, they agreed on criteria for identifying caregivers (must be age 18-45 and educated through at least grade 8), and established HBC organizing committees. Each committee would have five members per idir, two of whom must be women. Caregivers, who are not paid, are required to report to their idir's weekly HBC committee meeting. HBC committee members later received two additional days of training specifically on management. This training covered monitoring and evaluation, volunteer coordination, and records systems. To help them grasp the impact their work could have, FHI bused committee members about 250 kilometers out of Addis Ababa to observe an idir that had initiated care and support activities on its own. Seeing first-hand how these services could be delivered through the idir structure caused some idirs to regret not having stepped forward earlier, Worknesh says.



The HBC program has unexpectedly prompted a huge cultural change among the idirs, which began to see they need not wait until a member dies to offer help. In the past year, many idirs have changed their bylaws to permit involvement in care and support activities. Instead of reserving funds for a member's survivor, many idirs have begun making the money available to the ill member while alive, helping him or her with food, medicine or other needs.

## TRAINING THE CAREGIVERS

To select the local NGO that would manage the home- and community based care program, FHI conducted several assessments of local care and support services. Selecting a skilled NGO was important because this group would take on a mentoring role to build idirs' capacity in these activities. FHI quickly identified HAPCSO as an ideal candidate. HAPCSO already had experience caring for PLHA and, although it operated in a limited geographic area, it was working "at ground-zero level," says Worknesh. "They worked very tight, close to the community, and that was important. Their capacity was limited, but they were doing an excellent job." The agreement with HAPCSO became official in September 2003 with a US\$340,000 contract for an initial 13.5 months.

Once HAPCSO and the idir societies were on board, the project began to hire nurses and train them in HBC delivery, simultaneously preparing many of them to instruct others. FHI helped build HAPCSO's capacity by incorporating Ministry of Health training materials into these activities and augmenting them with Amharic translations of new training modules on monitoring and evaluation and on caring for orphans and vulnerable children. The training was provided in three areas, delivered in sequence over three weeks:

- Theoretical—what HBC is and why it's important
- Demonstration in the classroom—some basic nursing skills, such as how to use gloves.
- Observing and delivering care to the critically ill at hospitals and in other HBC programs—bathing a patient, for instance

The Regional Health Bureau donated space at Ras Desta Hospital, where much of the HBC training now takes place. Here, FHI and HAPCSO have created a valuable link between government-run and community-based services. The project opened a home- and community-based care center in May 2004 that today boasts a large training/conference room, a medical supply center, counseling rooms, offices and a small library. Supplies for the HBC "kits" used by caregivers are funded by the Development Cooperation Ireland.

In the conference room, caregivers are taught how to provide nursing care, prepare meals, cleanse clients and help them with various tasks. All training is conducted in Amharic, the local working language, and is of such a high quality that the center receives requests for it from people unaffiliated with HAPCSO or FHI. Where possible, it honors these requests. The Global Fund has asked HAPCSO to train approximately 500 people from the Fund's NGO partners; HAPCSO plans to do so and the Fund will cover training costs. When a Coca-Cola factory asked

for help, a HAPCSO nurse supervisor arranged for volunteer caregivers to present an educational drama for factory workers. The 2,000 birr, or about US\$240, that the factory donated after the performance was distributed in small amounts to about 130 HBC beneficiaries.

In the first two quarters of operation, caregivers assisted 679 patients, mostly of whom are HIV-positive. Of those, 178 have died, reflecting the poverty, poor nutrition and late diagnosis of so many. As with Andarge, each patient typically receives a caregiver visit three times a week. The caregiver provides basic nursing care, offers psychosocial support, and facilitates referral links to other services in the community. Caregivers are also likely to wash clothes, clean house and prepare food. “Caregivers are everything to these people. They’re really filling a gap,” says Worknesh.

The nutritional crisis here is so severe that caregivers sometimes can do little else but bring food, often at their own expense. “For care and support to be complete, it must address all their needs. You can’t separate their economic situation. When you go into a household to give care and you find there’s nothing to eat, treatment is not enough,” says Ephrem Fikre, HAPCSO’s program coordinator. The program supports income-generating activities for women and orphans, and tries to provide some food to help meet basic nutritional needs.



*Yeshiemeбет Kassa manages the supplies that make up the “home-based care kits” for the project’s volunteer caregivers.*

HAPCSO and the idirs have been especially effective at drawing men into care-giving, traditionally a female role here. Men were made a priority in volunteer recruitment (as were people with HIV and older orphans), and now make up about 40 percent of the caregivers. “Everyone here is affected by HIV. The magnitude is so great and the suffering felt so keenly” that it extends beyond gender roles, says Alemu Tadesse, HAPCSO’s HBC nurse supervisor.

Because of the difficulty in keeping caregivers engaged in such emotionally and physically challenging work, HAPCSO has developed incentives. Caregivers are reimbursed for some minimal transportation costs, such as to attend HAPCSO review meetings. They receive a certificate for their commitment. Those who excel as caregivers for at least 18 months are sponsored in skill-training classes, where they may learn hairdressing, electronics, auto mechanics or teaching skills. (For this, HAPCSO pays an average of 2,500 birr each, or US\$300). And, in a region with high unemployment, they are considered for job opportunities on HAPCSO’s paid staff, as community social workers, for instance.

HAPCSO's role in this HBC program has made it a major stakeholder in HIV activities, and earned it recognition by the government and other NGOs. Indeed, the agency's work has not just improved lives and enabled the community to better care for those who are ill. Indirectly it has helped reshape the local health system. "The biggest thing we have done is not providing care or (running) the training program. It's that we made this agenda the agenda of the city government and the local community," says former HBC Project Coordinator Hailu Taye, a nurse and economist. For its outstanding efforts, FHI presented HAPCSO with an Access Award during the International AIDS Conference in Bangkok in July 2004.

These activities take place amidst stigma so pervasive that, even as HIV infections spread, "HIV" is sometimes not said aloud. In fact, a guide produced by the project was carefully titled the *Manual to Provide Home-Based Care for Chronically Ill Patients*. The stigma is evident in personal ways, too. Ephrem recalls a young woman who lost her husband to AIDS. So fearful was she of neighbors learning of her HIV infection that she kept herself isolated, practically confined to bed, for six years. Finally, in February 2004, when she was 25, HAPCSO caregivers reached her. To determine what services she could most benefit from, they asked her to take an HIV test. The result was negative. The woman had been free of HIV all along, but her fear of stigma caused her to forfeit years of her life. "Had it not been for the health care service we provide, the woman would not have known her status. The stigma attached to HIV is so great that people hide themselves, not even talking to others. Many die without getting any support," he says.

This case illustrates a unique aspect of the program: using atypical ways of finding those who need help. This woman was discovered by volunteer caregivers who go home-to-home trying to identify potential clients. In other cases, HAPCSO uses "coffee ceremonies" to spread word of its services. These are traditional events where discussions—part informative, part social—are held among neighbors who gather outdoors, perhaps under a big tree. The speakers might bring coffee, sugar or corn to those who attend. Usually 20-30 people from five or six households participate, but sometimes coffee ceremonies are organized in the home of someone with AIDS, and family members and neighbors congregate to share in the ceremony. As HIV has cut a greater swath through Ethiopian society, the coffee ceremonies' focus on AIDS has grown, too, explains Alemu.